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Discovering Family Concerns, Priorities, and Resources:

Sensitive Family Information Gathering

Manny and Jo Reyes, along with their two-year old daughter Kelsey, have just moved into your town. Kelsey has special needs, including physical disabilities that would benefit from physical therapy as well as other related services. She had been receiving these services from an early intervention agency in their former town, and was referred to you by a service provider from that program. You have arranged to meet Manny and Jo to gather information about Kelsey and their family before taking any further steps.

This will be the first time that you find yourself working with a family whose background is substantially different from your own. For example, Manny immigrated to this country as a young adult 15 years ago, while Jo is a first generation American in her family. In contrast, your family members are considered pioneers, having settled in the area over a century ago. You have lived most your life in the area, while Manny and Jo have lived for the last ten years in a large city by the coast. The three of you share English as a common language. Manny is fully bilingual and considers English his third language, being more fluent and comfortable in the two languages he learned growing up in his homeland.

These differences in background mean that you, Manny, and Jo will have similarities as well as differences in your beliefs, values, and practices concerning addressing Kelsey's needs. Meeting with Manny and Jo to gather information presents a unique experience in your career. Because your college training and ongoing staff development activities to date have not focused on issues related to interacting with families from a variety of backgrounds, you hope this practical experience will help you begin to develop skills and understanding in this area. In the process, you hope that you will begin to build a healthy and trusting relationship with the Reyes family and provide effective services to Kelsey.

Family information gathering is an important part of the process of providing early intervention services to children from birth to age three and their families. Rather than being viewed as a discrete activity, family information gathering might be best envisioned as an ongoing process through which the early intervention (EI) provider continuously refines his or her understanding of the family's resources, priorities, and concerns, both in relation to their child as well as potentially to broader family issues (Turnbull & Turnbull, 2001). An underlying premise is that each family is a system with all parts interrelated; therefore EI providers cannot focus solely on the child without considering the family (Hanson & Lynch, 1989; McCroskey, Nishimoto, & Subramanian, 1991). Researchers (e.g., Beatty, 1994; Garshelis & McConnell, 1993; Trivette, Dunst, Deal, & Hammer, 1990) suggest that engaging in family information gathering can help EI providers: (1) identify information that will empower families and get them invested in obtaining services for their child, (2) develop a collaborative and supportive relationship between EI staff and the family, (3) identify sources of family support that can be utilized during service provision, and (4) establish family needs in relation to their child. This will enable EI staff to enhance family engagement essential for relevant home-based activities by focusing service provision on goals and activities important to the family.

Family information gathering also is instrumental for individualizing early intervention service delivery. Given the goal of individualization, it is necessary to understand the impact of cultural, environmental, and social factors (e.g., background, socioeconomic status, education) on goals families have for their children and family as a whole. These factors may also influence families' views and beliefs about parenting, child-rearing practices, and early intervention services (Lotas, Penticuff, Medoff-Cooper, Brooten, & Brown, 1992).

This article provides an overview of the family information gathering process in early intervention, and the impact of cultural and linguistic diversity on family information gathering. Practical strategies that EI providers can use as well as implications for personnel preparation are discussed.

Individualizing Family Information Gathering

To work with families effectively, EI providers should consider the specific needs of each family and individualize their family information gathering approach to ensure that they address those needs. Four factors that impact the depth and timing in gathering family information include: (1) the family's cultural and/or linguistic background, (2) the family's current living situation, (3) each family member's personal preferences, and (4) the quality of the provider-family relationship, which can facilitate a comprehensive family information gathering approach that occurs naturally and informally over time.

The goal for EI providers is to identify with the family a comprehensive view of their needs, locate resources to meet those needs, and help them link with existing resources (Trivette, Deal, & Dunst, 1986; Turnbull & Turnbull, 2001). For some families, EI providers may need to take a broad view, going beyond identifying family needs, concerns, and priorities centered on the child to include identification of other more immediate and pressing family needs. For example, some families may need to secure housing and employment before they can concentrate fully on their child's overall development. For other families, the most appropriate approach is one that centers on issues related to their child. This minimizes the chance that family members feel EI providers are trying to assess the family's general functioning or are making the assumption that because there are concerns about the child there must also be concerns about the family (Slentz & Bricker, 1992).

An informal, conversational approach to family information gathering is supported by researchers who found that family members perceive EI providers as an important source of emotional support and friendship, with the implication being that early intervention will involve the development of personal relationships (Summers et al., 1990). EI providers might best utilize

some of the tools and strategies mentioned in this article over time as a part of developing personal relationships, rather than to rely on them in formal sessions devoted exclusively to family information gathering. Many EI providers utilize an informal approach to family information gathering through conversations and the sharing of stories over time, and the information provided in this article should be considered within that context.

Also, federal regulations stipulate that family information gathering is a voluntary activity for families. As defined in the Individuals with Disabilities Education Act (IDEA, 1997), "Family assessment [now known as family information gathering] ... must be family-directed and designed to determine the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the child" (Sec.303.322 (d) (1)). Specific child services can still be provided if the family does not choose to participate in interviews or discussions that focus on family needs, strengths, and priorities. Typically, the individualized family service plan (IFSP) is revised every six months; this creates natural opportunities to explore the possibility of engaging the family as they become more comfortable with the EI service delivery staff and system. For example, family members may at first be wary of participating in any family information gathering efforts. A few months later they may wish to talk about needs and priorities related to their child. Still later, they may wish to share with the EI provider broader family concerns they have regarding their child's future. Thus, it is critical that family information gathering be an ongoing process that develops as a result of the dynamic interchange between family members and EI providers (Bailey, 1996).

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Impact of Diversity on Family Information Gathering

Everyone is a member of a culture or cultures. Each family member, each EI provider, and each child views the world through culturally-tinted lenses that influence their social interactions, behaviors, beliefs, and values (Barrera, 2000). The norms and values by which families live affect their willingness to provide information to EI providers as well as their willingness to involve themselves in the overall family information gathering process. Thus, to ensure that

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EI providers establish healthy relationships with families, it is important that they gain a better understanding of and appreciation for the complexity of culture and language and how they may impact their relationships with families.

Family information gathering is most effective when conducted by EI providers who understand and respect the value systems and unique perspectives and beliefs of the family (Sprott, 1993). Through the family information gathering process, EI providers may begin to understand the family operation within the context of the cultural or linguistic groups with which family members affiliate. EI providers must be familiar with the cultural meanings and symbols specific to the family, which may require knowledge of the family's language or the assistance of an individual competent in the family's cultural or linguistic group (Lynch & Hanson, 1998).

EI providers, who recognize that their competence in understanding cultures and languages that are different from their own will always be somewhat limited, are likely to become lifelong

learners. Having a predisposition to learn from their repeated interactions with families and community members about beliefs and values regarding disability, early intervention, and participation in other social service systems will increase the EI provider's capacity to respond to individual family and child needs in a respectful, meaningful, and empowering way. For example, in the process of getting to know a family, the EI provider may learn that among members of the family's community, the ability to solve problems with minimal reliance on outside help is often viewed as a sign of individual strength and respect for a higher spiritual power. The EI provider may find that the family places great value on self-sufficiency, and prefers to keep family problems and issues private. Recognizing this value can help the EI provider use it as a starting point for addressing the child's needs.

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The majority of EI providers in the United States have Anglo/Euro-American backgrounds (Lynch & Hanson, 1998). The value of service providers sharing the same ethnic or cultural background as the families they serve seems logical, and is often advocated (e.g., Banks, 1997; Shapiro, 1996). However, Kalyanpur and Harry (1999) state, "There is no evidence that professionals who do belong to the same culture as their clients are any more successful at accomplishing collaborative relationships than those who do not ..." (p. 131). For example, Navajo parents expressed a high degree of general satisfaction with early intervention services (Applequist & Bailey, 2000). Studies completed with other ethnic groups also show no correlation between service providers' cultural backgrounds and parental satisfaction (McWilliam, McGhee, & Tocci, 1998).

The overall issue of trust applies to family information gathering as well as to other aspects of early intervention service provision. EI providers can show respect for cultures by being willing to understand that they have been shaped by their own experiences and by accepting differences between the backgrounds of the providers and family members (Kalyanpur & Harry, 1999). Thus, EI providers can strive for cultural competence, and be interested in learning from and about the families they serve.

For families who speak languages other than English, EI providers should offer services in the families' preferred language or through the assistance of a qualified translator or interpreter. This will not only increase the accuracy of information gathered, but will also show families that their culture and language are respected, thus encouraging further family participation. For example, if it were acceptable to the family, a member of the family's community might serve as a "broker" between the EI provider and the family. The role of this community member might be to interpret some of the family members' beliefs. In turn, this community member also could be the one to explain to the family members the information, options, and solutions offered by the EI program. The community member also can assist the EI provider by interpreting some of the EI provider's observations related to child or family issues.

Kochanek and Friedman (1988) suggest six questions that can guide EI providers when working with families whose cultural and linguistic backgrounds are different from their own and/or from that of the mainstream culture:

1. Is it acceptable for outsiders to be involved in family business?
2. What constitutes a concern legitimate enough for outsider involvement and what are the

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accompanying feelings for family members (e.g., embarrassment, anger, or resentment)?

3. Who is the "gatekeeper" in the family through whom all outsiders must go?
4. What are the normative routes for help-seeking and social support within the culture?
5. What is the meaning in the culture of having a child with a disability?
6. Do families served have adequate facility with the English language to ensure reliable and valid results? Must assessment tools be translated (and normed) into other languages for optimal results?

At the very least, acquiring knowledge about these issues prior to engaging in any sort of formal or informal information gathering strategy will be essential if the interactions with families from diverse cultural and linguistic backgrounds are to be respectful, positive, and productive.

Family Information Gathering Strategies

The professional literature and recommended practice documents have provided suggested strategies for conducting the information gathering process with families (Sandall, McLean, & Smith, 2000). The strategies include interviews, observations, and survey instruments. The EI professional may use one or more of these strategies and implement them in either a formal or informal format. The key is to match the strategy and format to family preferences.

Interviews

If conducted in a sensitive manner, interviews can allow families to tell their personal stories in their own way. Interview questions should be open-ended and modified based on the flow of conversation, thus making interviews a relatively flexible approach (Slentz & Bricker, 1992; Summers et al., 1990). For some families, formal interviews that occur early in the relationship may be problematic (Hanson, Lynch, & Wayman, 1990). Because real exchanges of information may be possible only after a comfortable relationship between the EI provider and the family members has been built, either more informal interviews or ongoing family conversations have been promoted as the most appropriate methods of initially gathering information about a family (Hanson & Lynch, 1989). These allow families greater control over what to share and give EI providers the opportunity to modify questions to accommodate individual families.

Later, a well-constructed and in-depth interview can provide an EI provider with valuable information that formal instruments often miss. Boone and Crais (1999) suggest that open-ended questions such as, "What does your child like or enjoy?" and "Do you have any questions or concerns about your child?" can help EI providers begin to understand the family's concerns, resources, and priorities.

They caution that often EI providers ask too much of families and/or do a poor job of explaining why the information might be useful. Some additional guidelines and suggestions for family interviewing can be found in Table 1.

Observation

Observation is useful when the EI provider would like to determine the rate, pattern, or quality of family-child behaviors, as they might relate to the eventual development of goals for the child and family (Bailey et al., 1986). Observations can be conducted with the assistance of formal tools, such as the "Home Observation for Measurement of the Environment (HOME)" (Caldwell & Bradley, 1984), or more frequently simply involve informal report writing typically associated with home visits with the child and family. Using formal observation tools may be viewed by some families, regardless of their background, as an invasion of privacy, threatening, or even demeaning. Some families may feel that specific aspects of their family's competence are being evaluated according to criteria with which they do not agree. Furthermore, serious ethical questions must be considered, such as determining whether the use of observational tools or approaches may cause inadequately trained EI providers to make judgments and recommendations without referencing them within the context of family and cultural values (Baird & Peterson, 1997). Finally, all

Table 1

Guidelines and Suggestions for Family Interviewing

1. Strongly consider adopting an ongoing conversational approach with families in lieu of formal family interviewing, as advocated by Summers et al. (1990).
2. Make the purpose of the interview clear to families prior to conducting the interview. For example, "The purpose of today's visit is for us to be able to learn from you about (Child's Name), about your family, and about concerns and needs you might have" (Winton & Bailey, 1988, p. 200).
3. Establish rapport with families prior to gathering information. Acknowledge all the people present and thank them for taking the time to meet with you. Share background information about yourself and your program (Dunst & Deal, 1995).
4. Utilize both open-ended and close-ended questions. An open-ended question such as, "Would you share with me what a typical bedtime is like with your child right now?" allows for unanticipated areas of concern to emerge.
5. Ask for details in a sensitive fashion. You might say, for example, "I noticed some doubt in your voice as we were talking about the possibility of surgery for your child. What are your concerns about this?" (Dunst & Deal, 1995, p. 100). Remember that family information gathering is a voluntary activity for families and that some families may view the process as an invasion of privacy or as threatening or demeaning.
6. Talk to as many family members as possible (e.g., parents, siblings, grandparents, and extended family when they have significant roles). When gathering information from families of diverse cultural backgrounds with which you are unfamiliar, it may be appropriate to ask a cultural guide or "broker" to aid you.
7. "Funnel" the information by starting with broad concerns and then getting more specific (e.g., ask, "Could you tell me a little bit more about her behavior?" Then ask, "Are there particular times of the day that the problems are more severe?"). Summarize what the family members are saying to ensure that you are interpreting accurately both feelings and content.
8. A "Conversation Guide" to promote relaxed and natural conversation with families is available in Appendix B of the book *Families, Professionals, and Exceptionality: Collaborating for Empowerment* (Turnbull & Turnbull, 2001).

observation must be done carefully. Even if EI providers do not use a formal observation tool (as is typically the case), the challenge of interpreting observations considering the family's viewpoint rather than only the perspective of the EI provider, who often differs in background, remains (Baird & Peterson, 1997).

Survey Instruments

Some early intervention programs utilize survey instruments to gather information from families. Tools such as the "Family Needs Scale" (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988), the "Family Interest Survey" (Bricker, 1993), and the "Family Needs Survey" (Bailey & Simeonsson, 1990) are designed to facilitate the identification of family needs and strengths to prioritize early intervention services. When used to guide family information gathering, survey instruments are not intended to serve any norm-referenced function or generate a quantitative score (Bailey & Blasco, 1990). Rather, survey instruments can help EI providers obtain information about family needs in a convenient and efficient way. Formal survey instruments may seem impersonal, or even evaluative, and many families may be more comfortable with the informal strategy of acquiring information over time through conversations. However, it is also possible that some families may prefer the efficiency of filling out survey forms on their own or in an interview format. Boone and Crais (1999) caution EI providers to pay attention to the literacy level and amount of jargon (e.g., terms such as pincer-grasp or object permanence) in formal tools, and believe that instruments that provide pictures or concrete examples of certain skills are preferable. As stressed throughout this article, family preferences should dictate the strategies used.

As mentioned previously in this article and validated by the work of Summers et al. (1990), strong consideration should be given to using these sorts of instruments as a guide rather than using them in a formal way. A tool such as the "Family Needs Scale" (Dunst et al., 1988) might assist the EI provider in guiding the conversation over time to issues identified on the survey form (e.g., importance the family places on special dental and medical care, or the need for respite care). When using survey instruments, there are some strategies that EI providers can use to make the family information gathering process more accurate and responsive to families. For example, EI providers can introduce the tools in an individualized and informal manner.

Formal interviewing, observation, and surveys should be used cautiously and only if that is the family preference; typically formal tools will only be used to guide the family information gathering process. The important concept to remember is that family information gathering efforts serve to focus intervention on concerns and issues identified by family members, and to communicate to family members that they are important and that their perceptions of their child are important (Baird & Peterson, 1997; Boone & Crais, 1999). The Culturally and Linguistically Appropriate Services (CLAS) Early Childhood Research Institute has developed guidelines that service providers may use to assist in evaluating the appropriateness of family information gathering tools and related materials (CLAS Institute, 2001). These guidelines are presented in Table 2 (see following page).

Family Information Gathering Issues in Personnel Development

It is not possible to prepare service providers for every possible situation that arises with families, and ongoing support is needed to help EI providers increase their abilities to respond to the unexpected in supportive and facilitative ways (Winton & Bailey, 1990). Often, a variety of models of effective personnel preparation methods are needed to combat problems of high turnover, low incidence of persons of color in the field, etc. (Hains, Lynch, & Hanson, 2000). Professional development strategies, for example, that have been implemented successfully include distance education through e-learning formats and/or trainers traveling to remote areas for training events and workshops for providers working in rural areas (Rowland, Rule, & Decker, 1996). Intensive short-term inservice

Table 2

Considerations When Using Family Information Gathering Instruments

1. Consider using family information gathering tools as a guide that suggest useful areas to explore rather than utilizing them more formally (e.g., reading all the questions of a survey form to family members, etc.).
2. Examine the literacy level of the tool. Some may not be appropriate for some families.
3. Consider whether the meaning of a response may not be clear or may affect the quality and accuracy of the information gathered. For example, on the original version of the "Family Needs Survey" (Bailey & Simeonsson, 1990), there were three response options: "Definitely Need Help," "Not Sure," and "Definitely Do Not Need Help." Many families did not like the term "definitely," while other families thought that checking a phrase that states they "need help" made them seem dependent on others and weak (Bailey, 1991).
4. Match the tool or instrument to the information gathering objective. Collaboration with other staff or agencies to determine which family information gathering tools have worked best in various situations may be a useful strategy.
5. Consider possible bias in the tool or instrument. For example, the "Home Observation for Measurement of the Environment (HOME)" (Caldwell & Bradley, 1984) has been criticized for favoring families with higher socioeconomic status (SES) (Hanson & Lynch, 1989). The CLAS Early Childhood Research Institute Web site (http://clas.uiuc.edu/review/RGFamilyInfoGathering.html) offers some guidelines to consider when selecting family information gathering tools or methods.
6. Use informal tools (as opposed to norm-referenced, standardized tools), such as those recommended in the *Guidelines and Recommended Practices for the Individualized Family Service Plan* (NECTAS & the Association for the Care of Children's Health, 1991) or *Practical Strategies for Family-Centered Early Intervention* (McWilliam, Winton, & Crais, 1996).

instruction on various aspects of interviewing related to family information gathering has also been implemented to enhance current professionals' skills (Winton & Bailey, 1988, 1990).

Both inservice and preservice professional development programs designed to teach providers to gather family information and engage in family-centered services effectively may need to stress that the personal style of the provider is crucial. Encouraging EI providers to develop patience in establishing relationships with family members and adopting an informal, conversational approach to family information gathering will help prepare providers to approach and interact with family members in nonjudgmental and respectful ways.

Conclusion

Family information gathering is an area that providers can approach in relatively flexible ways. While this flexibility can be beneficial for more experienced providers, it may well lead to confusion for inexperienced staff members. There is a significant risk of alienating families early in their relationship with EI providers by asking questions the family may regard as an invasion of their privacy. To prevent alienating families it is important that family members have control over the process of information gathering as well as the opportunity to indicate goals they have for their child and the services and supports they desire.

More generally, EI providers should use an approach to family information gathering that is the least intrusive and most suitable for each family. Family information gathering conducted over time in informal ways can help EI providers avoid promoting change that is greater than families wish to accept. Sensitivity to and respect for the cultural values of families when gathering information about their strengths and needs are crucial to the success of the process, as is flexibility in how such information is collected and when it is collected (Hanson, Lynch, & Wayman, 1990; Harry, 1992).

Notes

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